Attitudes to shared care for patients with dementia

Attitudes to Shared Care for Patients with Dementia: a survey of general practitioners

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ABSTRACT

Early diagnosis of dementia is important but implications for care shared between primary and secondary care remain uncertain. We explored attitudes and expectations of Edinburgh's general practitioners (GPs) regarding current sharing of care for dementia.

Surveys were distributed to all 335 Edinburgh GPs; 79.7% were returned. Attitudes and expectations were examined, specifically whether dementia care was currently appropriately shared. Two-thirds of GPs were sure of their role and a similar number felt that care was appropriately shared. The latter opinion was not associated with individual GP factors such as gender or length of time since qualification or local levels of deprivation. However there was a significant association with sector consultant psychiatrist ($F=2.79$, $df=6$, $p=0.012$) and with the proportion of the practice list diagnosed with dementia ($\rho=-0.13$, $p=0.038$).

The endangered relationship between GP and specialist could be a key target to improve shared care and early diagnosis of dementia.

INTRODUCTION

Dementia represents a growing public health concern and health and social care services will need to make radical changes in response to the projected increase in cases in the coming years (Ferri et al., 2005). The proportion of the UK population over 65 is estimated to increase to 23% by 2035 from 17% in 2010 (Office for National Statistics, 2011), with the post-war 'baby boom' generation yet to reach this age. Trends in Scotland reflect those in the rest of the UK with an increase of 30% estimated between 2001 and 2021.(Scottish Executive, 2001) The importance of early diagnosis of dementia has been strongly emphasised (Anderson et al., 2005; Department of Health, 2009; Scottish Government, 2010, 2011) but the implications for primary and secondary care have not been made explicit. The benefits of shared care in a variety of conditions are widely acknowledged (Lester, 2005). However it is unclear whether the current sharing of care in dementia is sustainable in the face of the projected massive increases in the over-65 population. It is imperative that a robust interface between primary and secondary care exists, so that integrated services can provide optimal dementia care. Understanding the factors that might underlie this interface is essential to ensure that care is appropriately and fairly distributed and to facilitate the unavoidable changes required to meet the growing need for dementia care. Therefore this study investigated attitudes and expectations of general practitioners (GPs) in Edinburgh regarding the interface between primary care and old age psychiatry services for patients with dementia to identify factors which influence the provision of shared care. Specifically we explored why Edinburgh GPs use old age psychiatry services, how current services are rated by these GPs, and potential underlying determinants of whether or not GPs feel that care for patients with dementia is appropriately shared.

METHODS

The sample population included all GPs in Edinburgh, whose name, practice and address were provided on the current register held by NHS Lothian. GP Registrars and GP Speciality Trainees were excluded because information regarding their placements was unavailable.

A survey was devised consisting of 26 questions examining 3 specific areas (see appendix). Section 1 included nine questions examining frequency of referral to old age psychiatry for various aspects of dementia care (e.g., risk assessment, access to cholinesterase inhibitors), with response on a five-point Likert scale, from 'refer often' to 'refer rarely'. Section 2 included seven questions examining routine clinical action prior to referral (e.g., blood tests, CT brain), responding on a five-point Likert scale from 'routinely' to 'never'. Section 3 included 10 questions examining opinions on service provision, responding on a five-point Likert scale from 'strongly agree' to 'strongly disagree'. Open comments were invited at the end of the questionnaire. Consultation with primary care was sought prior to distribution regarding usability and accessibility for the target population.

Surveys were distributed via Royal Mail, and were accompanied by a stamped addressed reply envelope to maximise response rate. In addition, a covering letter explaining the purpose of the study countersigned by the relevant sector Consultant was included. Each survey was marked with a unique identifier to assist data entry and analysis upon return. A further survey and reminder letter were sent to those GPs who had not responded at 4 weeks. Characteristics of responders and non-responders were compared using Student's t-test for continuous variables and χ^2 tests for categorical variables.

Individual GP gender and date of medical qualification were sought using GMC registration data and practice websites. Quality and Outcomes Framework (QOF) data were obtained for

participating practices from the Information and Services Division of NHS National Services Scotland. QOF is a voluntary system of financially-incentivised indicators (currently 134) of the quality of clinical care, organisation, patient experience, and additional services in primary care in the UK (Lester & Campbell, 2010; Roland, 2004). This system is intended to encourage high quality primary care for the entire population by rewarding good practice. QOF indicator DEM1 records the proportion of the GP practice list registered as having dementia. QOF indicator DEM2 records the proportion of those patients registered with dementia who have been reviewed within 15 months. Scottish Index of Multiple Deprivation (SIMD) data were derived from practice postcodes using the Scottish Neighbourhood Statistics datazone conversion tool (Scottish Government, 2009).

In order to examine factors influencing the interface between primary and secondary care, we focused specifically on the question 'Care is appropriately shared between primary and secondary care services.' The association of responses to this question (mean from the five-point Likert scale) with individual GP and practice factors were examined using Student's t-test (gender), Spearman's correlation (year of qualification and QOF data) and one-way ANOVA (SIMD quintile for practice and sector consultant psychiatrist responsible for that practice). Data were anonymised and analysed using PASW Statistics version 18.0 (SPSS Inc., Illinois, USA). The South East Scotland Research Ethics Service were consulted and advised that the study did not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees in the UK.

RESULTS

335 questionnaires were distributed and 267 (79.7%) returned. There were no statistical differences between responders and non-responders (Table 1). Two questionnaires returned had no answers and so the analytic sample comprised 265 (79.1%) individuals. Gender and year of

qualification was not sought on the questionnaire for reasons of space and so data was obtained from the GMC register for 263 (99%) of responders. It was not possible to obtain information from the GMC register for 4 practitioners due to multiple individuals with identical names being entered on the register. 250 (94%) GPs participated in the QOF, therefore DEM1 and DEM2 records were unavailable for 17 (6%) practitioners. Individuals with missing data were excluded on a case-by-case basis.

Section 1: Frequency of referral to old age psychiatry

Table 2 outlines GP's responses to this section. The most common reasons for referral to old age psychiatry services (answered with 'I refer often') were in order to access cholinesterase inhibitors (78.8%) and to establish the diagnosis of dementia (67.3%).

Section 2: Clinical action prior to referral

The majority of GP's routinely undertook routine blood tests (94.7%), obtained a collateral history (88.7%), formally assessed cognition (77.4%) and told the patient/relative the likely diagnosis (67.0%) prior to referral to old age psychiatry. Only 3.8% arranged for a CT brain scan prior to referral.

Section 3: Opinions on service provision

Table 3 outlines GP's responses to this section. Nearly all GPs (91.6%) agreed that patients benefited from referral to an old age psychiatrist. 80-90% of GPs felt that there were clear communication channels between primary and secondary care. There was concern over the accessibility of inpatient beds with 81% of GPs feeling that they were not easily accessible. Understanding of their own role and the appropriate sharing of care between primary and secondary are services was good (66.3 and 65.3% respectively).

Factors influencing provision of shared care

More focussed analysis of answers to the question 'Care is appropriately shared between primary and secondary care services' are shown in table 4. No associations with individual GP factors (date of qualification or gender) or with deprivation level of the practice were revealed. However the sector consultant psychiatrist responsible for the practice was significantly associated with agreement that care was appropriately shared ($F = 2.79$, $df = 6$, $p = 0.012$) as was QOF indicator DEM 1 ($\rho = -0.13$, $p = 0.038$).

DISCUSSION

Summary of main findings

GPs in Edinburgh carry out investigations on behalf of patients with suspected dementia in line with good practice guidance (Suresh, Smalley, & Walker, 2008) and refer them to old age psychiatry for diagnosis and to access cholinesterase inhibitors (which in NHS Lothian are prescribed under a shared care protocol). GPs were generally in favour of old age psychiatry services but felt inpatient beds were inaccessible. Only two thirds of GPs were sure of their role in the shared care of dementia and a similar number felt that care was appropriately shared. The latter opinion was not associated with individual GP factors, such as gender or length of time since qualification or local levels of deprivation, which might have been expected to relate to shared care. Area-level deprivation has previously been shown to be associated with lower quality of primary care (Ashworth & Armstrong, 2006). However there was a significant association with sector consultant psychiatrist and a positive correlation with QOF indicator DEM1 (which records the proportion of the practice list diagnosed with dementia).

Strengths and limitations of the study

The current study obtained the views of a high proportion (79.7%) of GPs in Edinburgh, a city comparable in socio-economic mix to other cities in the UK though perhaps less ethnically

diverse—the 2001 census identified 95.5% people in Scotland as 'White British' compared to 87.5% for England and Wales (Office of the Chief Statistician, 2004). Our findings are therefore generalisable to many other cities, though less so to more rural areas and areas with larger geographical distance from secondary services.

The GP sampling method did not include GP registrars or speciality trainees. Though the register used was the most complete list available from a central and accurate source, it may not have included every GP working in Edinburgh, for example locum GPs. However the study's conclusions are likely to be generalisable to all urban GPs, as the majority of Edinburgh GPs were included in the study. Non-responders were similar to responders, suggesting that response bias did not affect the results. Demographic data were collected using indirect meansm, as outlined in the methods section, to avoid the questionnaire becoming too long. Details for four GPs (1%) were not available from the GMC register due to ambiguity. QOF data were unavailable for 17 (6%) GPs.

The survey questions were developed in consultation with a local GP and local Consultant Psychiatrists in order to focus on areas of interest to both groups. While the survey focused on the area of interest (the interface between primary and secondary care in dementia), the questionnaire was devised for the current study and may not have wider validity.

Our excellent response rate (79.7%) was due to several factors: expert consultation in developing the questionnaire, the importance of the topic, and facilitation of reply. The former was achieved as described above and ensured relevance to all interested parties. No one denies the public health significance of dementia and effective care and a cover letter on NHS paper countersigned by the sector consultant psychiatrist added their support to the importance of the survey. The involvement of the sector consultant might potentially have biased answers to

questions regarding the local service but it was felt that their involvement would, on balance, improve the response rate. Finally, replies were facilitated by including a stamped, addressed envelope and by sending a second wave of questionnaires and reply envelopes to those who initially didn't respond.

Comparison with existing literature

Few other studies have examined GPs' attitudes to shared care for dementia. Unlike the present study a large Irish survey of GPs' attitudes to screening and diagnosing dementia found that age and gender were significantly associated with "barriers to diagnosis " (Cahill, Clark, Walsh, O'Connel, & Lawlor, 2006). The main barriers to diagnosis identified in this study were differentiating normal ageing and dementia, lacking the confidence to diagnose and concerns about the effect of a diagnosis on the patient. Indeed concerns about disclosing a diagnosis of dementia to patients are not uncommon in primary care (Downs, Clibbens, Rae, Cook, & Woods, 2002). The Irish sample was from all GPs in Ireland as opposed to the current study approaching the whole population of Edinburgh GPs. Since our population was purely urban, it is not possible to comment on possible confounding by levels of rurality. Furthermore it is interesting to note that inner-city London GPs' favoured shared care for mental health in general less than their suburban colleagues (Brown, Weich, Downes-Grainger, & Goldberg, 1999). While the current study only approached GPs from a single city we were able to take area deprivation into account in the analyses.

Shared care has been defined as "shared responsibility, enhanced information exchange, continuing medical education, and explicit guidelines between a hospital outpatient clinic and primary care [and appears to be] a rational division of labour within medical systems dealing with long-term medical problems" (Iliffe, Wilcock, & Haworth, 2006, p. 353). The respective roles of primary care and secondary care in dementia have not been explicitly defined though attempts

have been made to operationalise the interface between GPs and specialists (Villars et al., 2010) or diagnose dementia with a co-operative "two-step process"(Waldemar et al., 2007) and in many parts of the UK shared dementia care, or at least prescription of cholinesterase inhibitors, is formalised in the form of a shared care protocol.

The importance of early diagnosis and management of dementia has been strongly emphasised in a number of government documents across the UK (Scottish Government, 2010) and effective shared care is fundamental to people with dementia being diagnosed early. In line with the rest of the country, The Scottish Government dementia HEAT target (national health priorities with explicit targets) requires health boards to increase the early diagnosis—by 33% in the first instance (Scottish Government, 2011). Similarly both the Scottish Dementia Strategy (Scottish Government, 2010) and the English National Dementia Strategy (Department of Health, 2009) highlight the importance of early diagnosis, while noting the possibility of 'false positive' diagnoses and consequent anxiety and social withdrawal. However these documents also highlight the importance of post-diagnostic information and support. Any effort at increasing rates of early diagnosis without mechanisms to inform and support the individuals diagnosed and their families risks causing unnecessary burden and distress. Further potential negative consequences of an early diagnosis include paternalism, stigma, medication side-effects, further strain on families as individuals live at home with their diagnosis for longer and, of course, greater demands on services (Iliffe & Manthorpe, 2004). These potential hazards result in some clinicians disputing the value of early diagnosis (Logan, 2005), though such opinions are becoming rarer (Milne, Hamilton-West, & Hatzidimitriadou, 2005). However, while acknowledging the potential risks, the benefits of early diagnosis are widely regarded as outweighing them, not least in providing the opportunity to plan for the future (Wilkinson, 2001). Nevertheless screening is not currently recommended, partly due to widespread, but misplaced, therapeutic nihilism (Brayne, Fox, & Boustani, 2007).

Implications for future research or clinical practice

The association of satisfaction with shared care and sector consultant psychiatrist found in the present study highlights the importance of the relationship between individual GPs and specialists. This is a timely finding when many old age services are considering, partly in response to the new UK equality legislation, redesigning services into specialist teams (e.g., intensive home treatment teams) with separate inpatient and outpatient consultant psychiatrists. The consequent loss of continuity of care these changes would involve compared to a sector-based model with a consultant psychiatrist responsible for each sector may have unexpected effects on shared care for dementia.

Furthermore the GP-specialist relationship provides a specific focus for targeting efforts to improve shared care for dementia and combatting therapeutic nihilism. GPs are more likely to diagnose or refer patients with suspected dementia if they feel this would be beneficial to the individual (Hansen, Hughes, Routley, & Robinson, 2008). Indeed many of the obstacles to dementia diagnosis identified in the literature relate to attitudes of primary care clinicians, e.g. whether a patient will benefit from intervention at a particular stage of the disease (Hansen, et al., 2008; Vernooij Dassen et al., 2005). A further barrier is GPs feeling that they lack the expertise to diagnose dementia. Both of these are opportunities for intervention using the GP-specialist relationship to provide education and training. Indeed only two thirds of GPs surveyed were sure of their role in dementia care but many commented how they wished to be empowered to look after their own patients, rather than expecting old age psychiatry to take over their care.

Satisfaction with shared care was greater in areas with higher QOF indicator DEM1, i.e., where a higher proportion of the practice list was diagnosed with dementia. This finding can be

interpreted a number of ways. Since approximately half of people in the community with dementia do not have a diagnosis (Sampson, Blanchard, Jones, Tookman, & King, 2009), DEM1 will not closely relate to dementia prevalence, particularly since neighbouring practices, which would be expected to have a similar prevalence of dementia in their population, can have widely differing DEM1 indicators. In fact, DEM1 could be interpreted as an index of quality of primary care or, at least, interest in dementia in that particular practice. This suggests that GPs who provide better care for people with dementia were more likely to feel that care was appropriately shared, highlighting the mutual nature of shared care. This finding, together with the importance of the relationship with the individual consultant psychiatrist already identified, suggests that there might be a synergistic relationship between primary and secondary care—a good GP and specialist provide even better shared care than would be expected from either service considered in isolation.

CONCLUSION

This study highlights the importance of the relationship between GP and specialist, suggesting that strengthening this relationship could be a key target in order to improve shared care and hence early diagnosis of dementia. Further interventional studies are necessary to provide evidence to support this hypothesis.

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Table 1. Comparison of GPs responding to the survey and non-responders

		Responders	Non-responders	Test statistic
Number (%)		267 (79.7)	68 (20.2)	
% male[1]		49	45	χ^2=4.2, p=0.24
Year of graduation[1] (median)		1985	1983	t=-0.17, p=0.99
Sector consultant	A	16%	9%	
	B	15%	19%	
	C	14%	19%	
	D	6%	9%	
	E	19%	7%	
	F	16%	15%	
	G	14%	22%	χ^2=10.8, p=0.09
DEM1[3] mean (SD)[2]		0.67 (0.5)	0.65 (0.4)	t=-0.43, p=0.67
DEM2[3] mean (SD)[2]		80.4 (19.6)	75.4 (27.0)	t=-1.72, p=0.089
Deprivation quintile (SIMD[3])	1 (most)	20%	21%	
	2	12%	13%	
	3	16%	25%	
	4	15%	10%	
	5 (least)	38%	31%	χ^2=6.1, p=0.19

[1] N = 264 (responders), 65 (non-responders)
[2] N = 250 (responders), 63 (non-responders)
[3] Dementia targets from the Quality Outcomes Framework
[4] Scottish Index of Multiple Deprivation

Table 2. How often do you refer to old age psychiatry for each of the following reasons?

For this reason …	*I refer often ↔ I refer rarely*		
	1–2	3	4–5
Access to cholinesterase inhibitors N (%)	208 (78.8)	31 (11.7)	25 (9.5)
To establish a diagnosis of dementia N (%)	177 (67.3)	50 (19.0)	36 (13.7%)
Carer stress N (%)	124 (47.5)	97 (37.2)	40 (15.3)
Request by others N (%)	109 (43.1)	98 (38.7)	46 (18.2)
Differentiate type of dementia N (%)	108 (41.2)	69 (26.3)	85 (32.4)
Exclude other mental illness N (%)	107 (40.5)	86 (32.6)	71 (26.9)
Need for additional services N (%)	89 (34.6)	76 (29.6)	92 (35.8)
Assessment of risk N (%)	72 (27.9)	88 (34.1)	98 (38.0)
Other N (%)	10 (31.2)	4 (12.5)	18 (56.3)

Table 3. Regarding service provision, do you agree with the following statements?

For this reason …	*Strongly agree* ↔ *Strongly disagree*		
	1–2	3	4–5
Patients benefit from referral to old age psychiatry N (%)	241 (91.6)	20 (7.6)	2 (0.8)
The outcome of a referral is communicated clearly N (%)	230 (87.1)	24 (9.1)	10 (3.8)
I am clear as to which service I should refer a patient N (%)	213 (80.7)	25 (9.5)	26 (9.8)
I receive a prompt response to referrals made N (%)	212 (80.3)	35 (13.3)	17 (6.4)
I prefer a single point of referral N (%)	206 (78.6)	40 (15.3)	16 (6.1)
All patients with a possible diagnosis of dementia should be seen by a psychiatrist N (%)	185 (70.1)	52 (19.1)	27 (10.2)
I am clear about my role in the care of patients with dementia N (%)	175 (66.3)	78 (29.5)	11 (4.2)
Care is appropriately shared between primary and secondary care services N (%)	171 (65.3)	72 (27.5)	19 (7.3)
I prefer referring to a specific professional N (%)	139 (53.5)	64 (24.6)	57 (21.9)
Inpatient care is easily accessible N (%)	50 (18.9)	89 (33.7)	125 (47.3)

Table 4. Care is appropriately shared between primary and secondary care services

		Agree N (%)	*Neither agree nor disagree N (%)*	*Disagree N (%)*	*Mean score (sd)*	*Test statistic (p)*
Sex	*Male*	82 (63.1)	37 (28.5)	11 (8.5)	2.19 (0.83)	
	Female	86 (67.2)	34 (26.6)	8 (6.3)	2.26 (0.87)	t=-0.7, p=0.48
Graduation year	*≤1985*	87 (64.0)	41 (30.1)	8 (5.9)	2.22 (0.83)	
	>1985	81 (66.4)	30 (24.6)	11 (9.0)	2.24 (0.86)	ρ=-0.01, p=0.84
SIMD quintile	*1*	33 (63.5)	13 (25.0)	6 (11.5)	2.35 (0.85)	
	2	19 (63.3)	9 (30.0)	2 (6.7)	2.27 (0.83)	
	3	23 (57.5)	16 (40.0)	1 (2.5)	2.25 (0.81)	
	4	23 (59.0)	13 (33.3)	3 (7.7)	2.38 (0.78)	
	5	73 (72.3)	21 (20.8)	7 (6.9)	2.07 (0.88)	F=1.50, p=0.20
DEM1	*≤ 0.5*	75 (61.0)	37 (30.1)	11 (8.9)	2.30 (0.87)	
	> 0.5	85 (69.1)	32 (26.0)	6 (4.9)	2.12 (0.83)	ρ=-0.13, p=0.038
DEM2	*≤ 80.0*	59 (59.0)	36 (36.0)	5 (5.0)	2.26 (0.84)	
	> 80.0	101 (69.2)	33 (22.6)	12 (8.2)	2.18 (0.86)	ρ=-0.03, p=0.65
Consultant	*1*	33 (76.7)	9 (20.9)	1 (2.3)	1.98 (0.77)	
	2	26 (66.7)	10 (25.6)	3 (7.7)	2.21 (0.86)	
	3	26 (70.3)	11 (29.7)	0 (0.0)	2.14 (0.67)	
	4	7 (41.2)	6 (35.3)	4 (23.5)	2.76 (0.90)	
	5	35 (72.9)	11 (22.9)	2 (4.2)	2.06 (0.81)	
	6	22 (55.0)	11 (27.5)	7 (17.5)	2.45 (0.99)	
	7	22 (57.9)	14 (36.8)	2 (5.3)	2.32 (0.81)	F=2.79, p=0.012

APPENDIX: Survey sent to GPs

Survey of Primary:Secondary Care Interface in Dementia

We would be very grateful if you would complete this survey about reasons you refer to old age psychiatry, your current experience of it and what you would like to get from the service.

Thank you very much for your help!
Please note there are two pages.

1. Regarding patients with cognitive impairment, how often do you refer to old age psychiatry for each of the following reasons? Please tick the appropriate box for each question.

For this reason:	*I refer often* ⟷ *I refer rarely*				
To establish diagnosis of dementia	☐	☐	☐	☐	☐
Differentiate *type* of dementia	☐	☐	☐	☐	☐
Exclude other mental illness e.g. depression	☐	☐	☐	☐	☐
Assessment of risk	☐	☐	☐	☐	☐
Access to cholinesterase inhibitors	☐	☐	☐	☐	☐
Carer stress	☐	☐	☐	☐	☐
Request by other: (e.g. family/patient/other agency)	☐	☐	☐	☐	☐
Need for additional services: (e.g. SW, OT, day care)	☐	☐	☐	☐	☐
Other (please specify)	☐	☐	☐	☐	☐

2. How likely are you to carry out the following prior to referral?

	Routinely ⟷ *Never*				
Routine blood tests	☐	☐	☐	☐	☐
Formally assess cognition using: (please specify tool)	☐	☐	☐	☐	☐
Collateral history	☐	☐	☐	☐	☐
CT brain	☐	☐	☐	☐	☐
Telling patient/relative possible diagnosis	☐	☐	☐	☐	☐
Referral to other health professional (e.g. OT, SW)	☐	☐	☐	☐	☐
Other (please specify)	☐	☐	☐	☐	☐

3. Regarding service provision, please indicate your response to the following statements:

	Strongly agree ⟷ *Strongly disagree*				
All patients with a possible diagnosis of dementia should be seen by a psychiatrist	☐	☐	☐	☐	☐
I am clear to which service I should refer a patient (*e.g.* old age psychiatry, adult psychiatry, geriatric medicine)	☐	☐	☐	☐	☐
I prefer a single point of referral	☐	☐	☐	☐	☐
I prefer referring to a specific professional (e.g. Consultant, CPN, SW, OT, Psychologist)	☐	☐	☐	☐	☐
I am clear about my role in the care of patients with dementia	☐	☐	☐	☐	☐
Care is appropriately shared between primary and secondary care services	☐	☐	☐	☐	☐
I receive a prompt response to referrals made	☐	☐	☐	☐	☐
The outcome of a referral is communicated clearly	☐	☐	☐	☐	☐
Inpatient care is easily accessible	☐	☐	☐	☐	☐
Patients benefit from referral to old age psychiatry	☐	☐	☐	☐	☐

Other Comments: